Hope and hopelessness: theory and reality

Thaïs Helène Downman

4 Wendover Drive, New Malden, Surrey KT3 6RN, UK. E-mail c/o: finlayi@parliament.uk

DECLARATIONS

Competing interests
THD's daughter is currently President of the Royal Society of Medicine

Funding
None

Ethical approval
Not applicable

Guarantor
THD

Contributorship
THD is the sole contributor

Acknowledgements
THD is 86 years old and retired

Introduction

Hope is a positive outlook on life experienced by us all at times, though it is not a permanent state of mind like optimism or its opposite, pessimism. It has been referred to by many philosophers, including some optimists, like Gottfried Leibnitz, who held that we live in the best of all possible worlds, created by God.[1] This theodicy was mocked resoundingly by Voltaire in his play *Candide*. The anarchist philosopher William Godwin espoused a utilitarian approach, and hoped optimistically that society would eventually reach the state where calm reason would replace all violence and force.[2] Such secular views embody concepts of hope in projections for the future.

From a non-secular view, hope comes within faith and it is one of the virtues '*Faith, Hope and Charity*'. Consequently it is linked to thoughts about the future and, for some, after death. In our attitude to life and expression of our thoughts, communication is very important. This communication may be direct with our fellow beings or through a belief in thought transference or prayer.

Realistic hope

Realistic hope is much more of an active analytical process. It involves an assessment of the future, perseverance, expectancy and an appraisal of all the various possibilities and their consequences which can promote the realization of the hope and its expectancy. It is an important ingredient of living and of a fulfilled life. Obvious examples are the desire for a healthy baby, a hope which should entail taking steps towards it through healthy living. Another example was of the prisoners in Colditz, hoping for their escape and taking active consequent planning to do so. Thus realistic hope is an active process with the intent and possibility of fulfilment and an assessment of what can and what cannot be changed. It thereby promotes 'will' to carry out some action and encourages engagement; as the 18th century philosopher Edmund Burke said, '*For the triumph of Evil it only requires that good men do nothing*'. Hope is realistic when considering that its fulfilment may alter the course of the future. In hope we strive for an ultimate preponderance of what we believe to be good and in that sense, judgement is continuous. The emotions and mental attitude are complex, far reaching. Hope also means 'looking forward' and contributes to being medically compliant.

Unrealistic hope

Unrealistic hope, in contrast to the above, it is a passive wish which may cause despair. It may be fantasy and carries with it negative feelings. Even with perseverance and will, the failure to acknowledge realistic properties means frustration, disappointment and possible anger. It is different from pessimism, which is more of a natural disposition to believe that things will turn out badly. Hence, the expectancy of fulfilment is constantly thwarted. It involves a failure to clearly assess what can be changed and what cannot be changed. Obvious examples can be found in individuals imprisoned by social conventions. Because of the negative thoughts engendered, unrealistic hope leads to a failure to try possibilities and opportunities to restore hope which is realistic. Unrealistic hope leads to a feeling of despondency and a loss of meaning in life. Whilst hope is a normal feeling to look into the future, hopelessness – which is different, though carrying the feeling of loss of meaning and purpose – is not normal. When things are bad, it is believed that this situation will stay the same forever.

Hope is important in palliative care, particularly as people are very ill and moving towards the end of life. Webster's definition[3] of hope offers two competing interpretations: one is of trust and reliance, which implies faith and dependence, as well as the belief that whatever the outcome, it will be for the best. This trust and reliance protects the person from loneliness and the feeling of being abandoned. The physician's presence and caring engenders hope. Terminally ill patients have

defined hope as an inner power directed forward towards enrichment of being. The other interpretation is a desire accompanied by expectation or a belief in fulfilment. Here, what separates hope from desire is the expectation of fulfilment which may be rational, but not necessarily so. But if hope is truly embodied in expectation, it creates miracles defying physicians' distrust in the light of realistic data. Hope is like a personal cheerleader in the game of life. There are many examples in medicine. One case described to me by a doctor was of a patient suffering from a rare, very serious cancer, who was given six months to live by the oncologist. When the patient asked his GP whether he knew of any alternative treatment, the latter conceded that whilst he did not know of any, this did not mean that no alternative treatment existed. This gave the patient the resolve he needed and he said, 'Well, I am going to find something.' In fact, he found some alternative medical treatment and he came back full of confidence and hope. He survived for another three years.

Finally, research by Breitbart and Heller[4] on terminally ill patients and meaning-centred psychotherapy found that depression, psychosocial factors and financial problems, concern about being a burden and hopelessness were very important factors. Seeing no meaning or value in living hastened their wish to die. In fact, spiritual wellbeing, in particular loss of meaning, are vital factors in despair. The importance of a sense of meaning and purpose is a vital component of the human experience. It gives a sense of wellbeing, of peace and contentment and facilitates a self-transcendence and connectedness with others who matter to us and something greater than oneself. It helps us to maintain our dignity, honour and esteem. For some people it is expressed in a religious context, but to others, by traditional medical and mental care providers. This research concluded that meaning-centred intervention increased spiritual wellbeing and a sense of meaning, reducing hopelessness and a desire for death. A sense of meaning and purpose has also been described in *Man's Search for Meaning* by the psychiatrist Viktor Frankl,[5] who survived in a concentration camp.

Reality

All this is as a preliminary to my own experience of terminal illness and the desire to die. Radiotherapy to my bone metastases brought no relief, simply making me feel sick, very weak and debilitated and with bowel problems that were undignified; my maximum package of home care could not cope. When I was admitted to the Princess Alice Hospice early in 2006, my only wish was to die. The pain was severe, and excruciating on any movement, and my general feeling so distressing that hope or expectancy did not enter my conscious mind. My only thought was to get out of living with the utmost expediency and the minimum of physical and mental awareness. Quality of life in the sense of meaning of life and purpose are all-important to me.

During that period, my family, and in particular my daughter, were very concerned and loving to me. My daughter, who is a palliative care practitioner, was at that time fighting Lord Joffe's Bill which sought to legalize assisted dying. After two to three weeks, my pain lessened so I began to feel a little better physically, but this also made me realize I was not just about to be released from my situation by death. This realization brought with it overwhelming thoughts about the emptiness of my future and the fear of being bedridden and a burden. I was of sound mind and certain that if I could take a lethal overdose to kill myself, I certainly would.

I was not happy at being alive and, when my daughter visited me and I expressed these feelings quite thoughtlessly, I suddenly became aware of how very deeply I had hurt her. It was as if within a moment I had destroyed her life's work. She was fighting for peace and dignity at the end of other people's lives and yet was now seeing her own mother regretting being alive. What did that say for her relentless work?

I felt terribly guilty and full of remorse: 'How could I do such a terrible thing, when I love her so and am so proud of her?' Fortunately, my dear son, calm and level-headed as his father was, resolved the situation and brought back peace. The emotional intensity during those few days was like a catharsis for me.

I resolved that I had to do everything in my power to get better. From being unable to walk more than a few feet, with the help and encouragement of the physiotherapist, the nurses and even total strangers, who witnessed my daily increasing walks up and down the corridor and who called out approvingly 'How many is it today?' or 'Are you training for the marathon?' I tackled stairs, gradually washing myself alone and slowly regaining some independence.

At the same time too, through the cards, flowers, and warm messages I realized that not only my family but others, too, genuinely did not want me to die. It was a kind of telepathic communication

where they had all congregated to increase the impact, but it was not until I found hope that my continued existence might have some purpose, that I was able to accept the sincerity of the kind messages.

My efforts to regain my former sense of wellbeing and independence have continued since and are still persisting. I gradually dispensed with my home carers and refused the offer of a stair lift and various bathroom gadgets. At first I walked just a few yards outside my house, gradually increasing the distances, pushing my wheelchair and only sitting back in it when too tired to proceed. Now I manage what I call my constitutional daily walk of about one and a half miles, taking about 40 minutes. I am receiving friends again, enjoy being taken out, shopping, visiting art exhibitions – partly in my wheelchair, but sadly not driving anymore. I admit, sometimes it requires a great effort to counteract my unwillingness or tiredness, but my fear of losing my mobility and being a burden spurs me on – but now to live, not to die! I bought a pretty, feminine walking stick decorated with colourful flowers, which for me epitomizes my acceptance and defiance.

My gratitude to Princess Alice Hospice, to all its staff, doctors, nurses, social workers, chaplains and volunteers, is far deeper than words can express. It is not only for the physical palliative care which I received, but for its profound mental and in particular spiritual help. It has revived my interest in philosophy and restored my faith in humanity – in the sense that I see that amidst all the exterior shallowness there is much goodness – and I have become aware that, if one is unhappy, one is selfish only thinking of one's own desires, but, if one feels at peace and contented, one's thoughts are for others, particularly those who love you. Now I find that I do not want to die yet; I feel I am still of some use to others and I hope my deterioration and end will not be too unbearable.

Finally, to end on a lighter note, not many people are fortunate, like me, to hear one's eulogies before lying in one's coffin!

References

1 Leibniz G. *Essais de Théodicée sur la bonté de Dieu, la liberté de l'homme et l'origine du mal* (Theodicy). 1710
2 Godwin W. *Enquiry Concerning Political Justice and its Influence on Morals and Happiness.* London: J. Watson; 1793
3 Webster's dictionary
4 Breitbart W, Heller K. Reframing hope: meaning-centered care for patients near the end of life. *J Palliative Med* 2003;**6**:979–88
5 Frankl VE. *Man's search for Meaning.* Washington: Washington Square Press; 1984